# Exploring the Link Between Public Involvement/Citizen Engagement and Quality Health Care

## A Review and Analysis of the Current Literature

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## Exploring the Link Between Public Involvement / Citizen Engagement and Quality Health Care

### Executive Summary

The purpose of this report is to present the results of a review and analysis of the literature linking public involvement/citizen engagement (PI/CE) and quality health care. The report addresses a number of key questions including: whether there is national and international evidence that support or refutes the hypothesis that PI/CE contributes to quality health care; in what way might PI/CE have an impact on quality health care; in what way might different types of PI/CE have an impact on quality health care; and are there models, approaches or strategies of PI/CE that are most likely to result in improved quality of health care.

The literature search conducted for this report entailed a review of national and international literature including Canada, the United States, United Kingdom, Australia and other Organization for Economic Co-operation and Development (OECD) countries and focused on the relationship between PI/CE and quality health care. Details of the search terms, specifics of the databases included in the search, limitations of the study and methods of analysis are identified in the report. Searches were conducted of: available electronic health and medical databases; medline; relevant online journal issues (1990-2003) and tables of contents; known items identified in publications reviewed by the consultants; keywords on Google search engine to obtain reports authored by government health ministries and agencies, as well as academic departments; recent papers on health reform in Canada; and reports specifically identified by Health Canada for review. Grey literature, polls and satisfaction surveys were not included in the search.

A number of key findings resulting from the review and analysis of the literature designed to better understand the link between public involvement/citizen engagement and quality health care are identified in the report and include:

- Many examples of PI/CE in health care decision-making are found in the national and international literature. The literature illustrates that many countries value PI/CE and have implemented different types of PI/CE in various aspects of the health care system.

- There is a great deal of variation and imprecision in the terms used to report about PI/CE.

- A number of typologies and frameworks classifying PI/CE in relation to health care decision-making have been developed, but have not been widely tested.

- A number of evaluation frameworks to assist in measuring the effectiveness of PI/CE in relation to health care or health outcomes have been developed, but their application has been limited.

- There are many examples in the literatures of reputed benefits of PI/CE in relation to health care or health outcomes.

- Overall, there is limited empirical evidence to support or refute the hypothesis that PI/CE contributes to quality health care. The evidence varies depending on the area or level of health care decision-making.

- The literature points to the public being a critical source of value identification for quality health care and outlines best methods for eliciting or aggregating these values. Shorter-term outcomes, where values identified by the public have been incorporated into key reports and documents, are prevalent. Whether the public's involvement in identification of values has a longer-term impact on quality health care is yet to be determined.

- There is evidence that involving patients in decision about their own care leads to improved quality health care or improved health outcomes when specific criteria are met.

- The public (patient/patient groups) have contributed to the planning and development of health care services across a range of service areas and levels and in many different countries, but the impact of this involvement on the quality and effectiveness of health services is undetermined.

- Health reform in many countries, in an attempt to increase accountability and citizen involvement, has led to regionalization schemes that involve citizens in regional and local health boards or councils. There appears to be no objective measures to verify whether or not regional health authorities or lay participation within these authorities has improved the effectiveness or efficiency or other quality aspects of health care.

- There is little research looking systematically at the publics' involvement in or preferences for being involved in particular types of rationing decisions or priority setting. Results from available studies are mixed or inconclusive. Some studies suggest the public is uncomfortable making resource allocation choices while others

indicate citizens acquire the necessary self-confidence and skills for deciding how resources should be allocated, if given sufficient time and adequate support.

- Over the past 40-50 years there have been major initiatives aimed at involving communities in addressing health and social issues. The literature illustrates that these collaborative community-based initiatives can have an impact on improving quality health care and health outcomes, but that this does not occur consistently. Analysis of these initiatives has contributed to the understanding of the key characteristics and conditions that lead to effective involvement at the community level.

- Certain types of PI/CE have greater potential to contribute to quality health care than others, such as deliberative dialogue methods and community collaborative practices. Using a combination of approaches lends itself to more effective PI/CE.

The report concludes that regardless of the type of PI/CE, for measurable impact on quality health care to occur, it is essential to pay attention to "getting the right participation" and "getting the participation right". Effective PI/CE is a matter of achieving the best fit.

Based on the review of the literature, the report presents the initial elements of a model of PI/CE that is most likely to result in improved quality health care: readiness, a common goal, the right participants, the right process, appropriate supports, the right leadership, and evaluation.

The report further suggests that more work is needed to consolidate a framework that represents the key features of PI/CE that are necessary to achieve and measure improvements in quality health care and health outcomes.

The report concludes by presenting a number of strategic actions that could be undertaken by government to enhance our knowledge, understanding, and success in linking PI/CE to quality health care.

# Exploring the Link Between Public Involvement / Citizen Engagement and Quality Health Care

## 1 Purpose and Scope of the Report

The purpose of this report is to present the results of a review and analysis of the literature linking public involvement/citizen engagement (PI/CE) and quality health care. The report addresses a number of key questions including: whether there is national and international evidence that support or refutes the hypothesis that PI/CE contributes to quality health care; in what way might PI/CE have an impact on quality health care; in what way might different types of PI/CE have an impact on quality health care; and are there models, approaches or strategies of PI/CE that are most likely to result in improved quality of health care.

## 2 Methodology

### 2.1 Parameters of the Literature Search

The literature search conducted for this report entailed a review of national and international literature including Canada, the United States, United Kingdom, Australia and other Organization for Economic Co-operation and Development (OECD) countries. The search focused on the link between PI/CE and quality health care. The following searches were conducted:

- Completed command line searching of the electronic health and medical databases available through DIALOG. This provided a mix of bibliographic and full text journal articles. The search terms used were grouped into four categories as follow: actors (citizen, public, community); action (involvement, participation, engagement, input, representation); agency (health care, health service, health management), and output (impact, effect, influence, relation, evaluation). Initially all possible variants of the terms were included in the search statement. To reduce these search results to more relevant information, field limits were employed. For example, in full-text databases, search terms were groups by parenthesis and the searches were limited to the following fields: titles, descriptors, abstracts or lead paragraphs only.

  *Note:* For the remainder of the searches below, phrase searching was generally employed, with the following phrases entered: public participation, public involvement, citizen participation, citizen involvement, in conjunction with health care, and health service.

- Used web search interfaces available on the University of British Columbia's library website (EBSCO, Ingenta, and ScienceDirect) to retrieve electronic full-text journal articles.

- Completed title/abstract searches of online journal issues (1990-2003) at each of the three primary medical journal websites: Canadian Medical Association Journal, Journal of the American Medical Association, and British Medical Journal.

- Scanned the table of contents of full-text health journals available online through the University of British Columbia's website to identify relevant articles. These included: Health Services Research, Health Expectations, Health Promotion International, Patient Education and Counselling, and Social Science & Medicine. As well, scanned Table of Contents of earlier printed editions of these journals, generally pre-1998.

- Conducted known item searching, that is, retrieved articles and reports from websites and online journals that have been identified in publications reviewed by the consultants and listed below.

- Conducted keyword searching on Google search engine to obtain reports authored by government health ministries and agencies, as well as academic departments. Government reports were obtained from the federal governments of Canada, the United Kingdom, Australia, and other OECD countries.

- Reviewed recent papers on health reform in Canada including: the Commission on the Future of Health Care in Canada conducted by Romanow (2002) and relevant discussion documents; the Senate Standing Committee on Social Affairs, Science and Technology (Kirby, 2002); the Report of the Premier's Advisory Council on Health for Alberta (Mazankowski, 2001); the Commission of the Study of Health and Social Services, Quebec (Claire, 2000); Commission on Medicare, Saskatchewan (Fyke, 2001); Health Services Review in New Brunswick (Sivret & Newbould, 2002); and reports specifically identified by Health Canada for review including Stroick (2002), Good Health Through Good Governance (2002), and the Canadian Blood Service (2002)

- Scanned Medline and searched terms public participation, public involvement, citizen participation, citizen involvement, in conjunction with health care quality assurance, monitoring or performance measurement.

### 2.2 Scope and Limitations

This review attempts to identify main themes running through the literature about PI/CE, quality health care, and the relationship between the two, as well as key initiatives from different countries known to involve citizens in health care decision-making. It does not make claims to be comprehensive in dealing with all literature on the subject because PI/CE and quality health care are each complex concepts and much has been written on each with considerable variation in how the concepts are defined.

This literature search did not include grey literature, polls or satisfaction surveys. Where secondary sources (such as critical reviews of evidence or government commissioned reports) provide valuable summaries of the literature on PI/CE and health care quality/decision-making these are noted and the original references not reviewed unless otherwise cited.

### 2.3 Analysis

Two researchers reviewed each journal article, abstract, summary or report to determine if it had any information relevant to this study. For each article of relevance, notes were made to identify the link between PI/CE and quality health care. In preparing these notes, the researchers looked in each reference for clarity in the way PI/CE was defined, who was involved for what purpose, the health care area or decision being addressed, the anticipated impact of PI/CE, and how the impact of PI/CE was measured.

Where a study illustrated some kind of impact of PI/CE on various aspects of health care or health care decision-making, these were noted. Attempts were made to identify the nature of the evidence such as: critical review of the literature, expert opinion, case study, qualitative or quantitative evaluation or other research methods. The researchers looked for and noted areas where there were common understandings, opinions and results or where there were inconsistent or contrary findings. In addition, corroboration of evidence was sought looking across countries, research methods, and disciplines or areas of practice.

## 3 Context

The purpose of this section is to provide an overview from the literature regarding what is meant by "public involvement", "citizen participation", or "citizen engagement" in health care decision-making, and how the term "quality health care" is defined in this document. A brief overview is included to provide some background regarding the extent to which

citizens are reported to be involved in health care service and systems decision-making nationally and internationally.

### 3.1 Definitions and Typologies of Public Involvement/ Citizen Engagement (PI/CE)

One of the major difficulties in examining the impact of PI/CE on quality health care is to clarify what is meant by these terms. There is much diversity in the way PI/CE is defined in the national and international literature. There is a great deal of variation and imprecision in the terms used and it is often not clear when recommendations are being made about PI/CE what type or level of involvement is being discussed. Does it refer to consulting the public through large public meetings or deliberative dialogue sessions with smaller groups of individuals? When reports call for greater public involvement, the intent or meaning could range from individuals having a greater say in managing their own health care, to involving the public in the planning and development of health care, to involving citizens in local health authorities or in defining values for the health care system.

Carol Kushner and Michael Rachlis (1998) identify a number of analytical frameworks that have been developed to assist in the understanding of consumer involvement. One framework by Robert Alford (1975) categorizes consumer involvement by interest groups, including dominant structural interests where groups are well organized to represent their members, repressed structural interests where interest are poorly served by existing arrangements, and challenging structural interests where interests emerge that challenge medicines professional monopoly.

Over the last 30 years, public involvement has been viewed as a continuum of approaches with different levels of involvement and with different techniques used to achieve the various levels of involvement. Stroick (2002) provides a summary of the theoretical typologies and operational models that have been developed, including one of the foundational typologies by Sherry Arnstein (1969), and the more recent work done in this area by Health Canada (2000).

The typologies presented share the common roots of Arnstein's ladder of involvement and build on it. Within these typologies, public involvement is most often used as the general term for the process of involving the public. There are different degrees or levels of involvement. The first or lowest level of involvement is usually regarded as one where the aim is to educate, inform or communicate and there is no transfer of power. For the middle level, the term public consultation is often used to refer to a degree of involvement where the goal is to promote the exchange of information between the public and the consulting organization. The top level is often

described as public participation and implies a more participatory type of public involvement process in which the public is a partner in the decision-making process. The main distinction between 'consultation' and 'participation' is the degree to which those involved in the process are allowed to influence, share, or control decision-making.

Citizen engagement is also a term currently being used. According to Philips and Orsini (2002), citizen engagement refers to a "*particular type of involvement characterized by an interactive and iterative process of deliberations among citizens and between citizens and government officials.*"

Charles and DeMaio (1993) argue for greater conceptual clarity in order to describe more precisely the various possible types and levels of public involvement or what they call 'lay participation' in different health care decision-making contexts. They build a multi-dimensional framework around three key variables. One variable is the level of participation in health care decision-making or the extent to which people have control over the decision-making process. This variable modifies the ladder of increasing citizen participation described in the works of Arnstein (1969) and Feingold (1977). A second variable refers to the type of health care decision-making 'context' or 'domain', such as the treatment or service system. The third variable identifies a 'role perspective' or the role a person adopts in the decision-making process, such as a patient (user), advocate, policy maker, etc.

Frameworks help to clarify the multiple dimensions and meanings of public involvement, and provide the opportunity to classify and analyze the various types of public involvement in relation to the various types of health care decision-making. Common frameworks provide systematic structures or analytical tools for evaluating the impact of specific types of involvement on specific types of health care decision-making. There have been a number of attempts to use a framework for classification, but few to apply such classification to evaluation of the impact of PI/CE on quality health care.

### 3.2 The Meaning of Quality Health Care as Used in this Report

Quality heath care is also a complex concept and can be considered from a number of different perspectives. Quality health care can mean, for example: providing appropriate care -"*the right service at the right time delivered by the right person in the right place*"; meeting accreditation standards as defined by the Canadian Council on Health Services Accreditation (their four dimensions of quality are responsiveness, system competency, client/community focus, and work life); using best practices as determined by health professional experts, tertiary/quaternary level

agencies and/or critical reviews of evidence; achieving improved health outcomes; and meeting the specific health needs of patients and their families, or the population health needs of the general public and communities. Health care decision-making that affects quality health can occur at different levels of the health care system such as: clinical, planning and development, defining and monitoring quality improvement, governance, priority setting and community development.

We have recognized that quality health care has a number of different meanings and for the purposes of this report we have used the broadest definition.

### 3.3 National and International Overview of PI/CE in Health Care

The notion of involving citizens in the process of defining their health needs and developing solutions to address these needs has been supported by the World Health Organization (1978), the Canadian Federal Government, and many of the Canadian provinces which have produced reports advocating for greater citizen participation in health care. Consumer participation in health also has an active history in the United States, Australia, the United Kingdom and in other Organization for Economic Co-operation and Development (OECD) member countries.

A number of key national and international examples of public involvement in health care are identified below to provide context and exemplify the extent to which PI/CE strategies have become part of the health care system. See also the work of Stroick (2002) who categorizes many national and international public involvement initiatives by degree of involvement. The examples outlined in this section are descriptive. The discussion of impact of PI/CE on quality health care from the identified countries is found in section 6.

#### 3.3.1 Canada

According to Philips and Orsini (2002), the challenge to involve citizen in policy processes increasingly became a central theme in discussions about modernizing governance. They indicate that the talk about involving citizens and reducing the democratic deficit seems to be everywhere. A number of notable examples are identified below.

The National Health Forum (1997, final report) was established in 1994 to involve and inform Canadians, and to advise the Federal Government on innovative ways to improve the health system and the health of the Canadian public. In a first phase, 1300 citizens across Canada were involved in 71 deliberative dialogue sessions designed to gain a better understanding of the public's views on key issues. In a second phase,

telephone surveys and regional conferences were used solicit input on potential solutions. The Forum used the public input, commissioned research, and extensive deliberations to determine the broad priorities for action.

The Social Union Framework in 1999 outlined an intergovernmental agreement between the federal government, nine provinces and the territories that for the first time included concrete commitments to providing opportunities for Canadians to participate in developing social and health priorities and reviewing outcomes.

Between 2000 and 2002, six provincial and federal reports were initiated in response to concerns about health care quality and system sustainability. These reports examine health care delivery, consider future needs and concerns, and make recommendations for change. In developing these recommendations governments engaged in processes that involved citizens to a greater or lesser extent. For example,

- The Standing Senate Committee on Social Affairs, Science and Technology (Kirby, 2002) held extensive public hearings and heard from a wide range of witnesses and received numerous briefs submitted on the topics under consideration.
- In New Brunswick, the Health Services Review Committee (Sivret/Newbould, 2002) used an extensive consultation process to determine the opinions of citizens in the province holding 25 public hearings and over 100 private sessions, conducting a public opinion survey and soliciting responses by e-mail and a 1-800 number, as well as seeking expert opinions.
- In Saskatchewan, the Commission on Medicare conducted by Kenneth Fyke (2001 Final Report) held public consultations to identify key challenges facing the people of Saskatchewan in reforming and improving Medicare. The Commission held consultations with approximately 200 members of the public in 19 different communities.
- In Quebec, the Commission of Study on Health and Social Services chaired by Michel Clair (2000) also derived their recommendations from consultations with the public, experts, and organizations.
- In Alberta, the Premier's Advisory Council on Health chaired by Don Mazankowski (2001) produced a report that included a section on addressing the identified concerns of Albertans but did not specify how these concerns were developed.

One of Canada's most recent and comprehensive examples of citizen engagement in health care planning is the Commission of the Future of Health Care in Canada conducted by Roy Romanow (2002). Romanow strongly believes that recommendations from the Commission should be based on the judgement of individual Canadians, and that the values underpinning Canadian's perceptions of the national health care system

need to be understood. The Commission implemented an extensive process to provide Canadians with a better understanding of the challenges confronting publicly funded health care, as well as choices and options available to them. A variety of opportunities were provided to engage the public in dialogue that would help shape the future of health care in Canada. Methods used included provision of information (televised policy forums on key subject areas, a Commission Workbook (Jackson et al. 2002) identifying four major options for the future and their pros and cons, web posting of research reports, discussion documents and the workbook); national dialogue (open public hearings across Canada); and deliberative dialogue sessions (12 sessions across Canada with 40 citizens at each).

A key recommendation from the Romanow Commission that may have implications for PI/CE is the establishment of a Health Council to provide leadership to achieve the best health outcomes. The Health Council is envisioned as providing advice on key areas of reform such as primary health care, the health workforce, use of technology, and resolving disputes. Most significantly the Council is envisioned as having an important role in ensuring accountability. This would include establishing indicators to measure performance, collect information and report to the public on efforts to improve quality, access, and health outcomes based on what the public values. Senator Kirby report also calls for a National Health Care Council. He recommends that a Commissioner oversee this Council and that the Council be responsible for producing an annual report on the state of the health system, and advise the Federal Government on how it should allocate new monies raised to reform and renew the health care system.

The Federal Government has indicated its commitment to providing Canadians with the Council that they have asked for, as outlined in the Romanow Commission. The aim is to have the Council, with representatives from government, the public and health professionals, in place by June 2003.

### 3.3.2 The United Kingdom

The United Kingdom exemplifies a strong commitment to PI/CE that is now legislated after many years of experience in public involvement initiatives (Health Development Agency, 2001; Harrison et al., 1998; Health Service Executive, 1999; Royal College of Practitioners, 2001) The results of the Inquiry into the management of the care of children receiving complex cardiac surgery at the Bristol Royal Infirmary between1984-1995 (2002) called for a national body to represent the public's interest. It concluded that the public's interest needs to be embedded into all the organizations and institutions concerned with quality of performance within

the National Health Service (NHS). This led to the establishment of a Commission for Patient and Public Involvement, which is a legislated government body that explicitly mandates consumer participation in policy, program and legislative processes.

The Commission is one element within the NHS Plan (United Kingdom Department of Health, 2002) that outlines strategies for greater public and patient involvement. There were already a number of opportunities for citizen participation in the Commission for Health Improvement (CHI), the National Institute for Clinical Excellence (NICE), and the NHS Research and Development Strategy. In addition the NHS plan calls for the establishment through legislation of Patients' Forums in every Primary Care Trust, National Health Services Trust and the Commission of Patient and Public Involvement in Health to set standards and provide training and guidance to build capacity for greater community involvement in the health service. These developments are currently being implemented.

The National Health Service of Scotland released a report called "*Our National Health: A Plan for Action, A Plan for Change*" in December 2000 that indicated it was no longer good enough simply to do things *to* people, but that health services must do things *with* people it serves. Public involvement was a major part of this plan. Subsequently a paper entitled "*Patient Focus and Public Involvement*" (2001) was released that identified policies to support public involvement in the National Health Service, and a three year funding commitment. These activities are currently underway, as well.

### 3.3.3 Australia

There are also many examples of initiatives incorporating PI/CE in health care in Australia (Commonwealth Department of Health and Aging, 2002; National Resource Centre for Consumer Participation in Health, 2002). However, expert opinion indicates that there are a number of factors that work against effective community participation in health care. For example, Butler et al. (1999) indicate that Australians tend to take a passive or spectator role with participation in the political sphere. Australians are reported to think about health issues in terms of 'what will government do about it', and government is seen as having a great deal of control over health decisions and expenditures. Yet, at both the state and federal levels, a number of community participation initiatives have been undertaken over the past 10 years.

The Consumers' Health Forum (2002) of Australia was established outside of government, but is highly dependent on government funds. It is made up of representatives from a wide range of consumer groups. It works to promote participatory research, improve quality of care

information for consumers, establish complaints bodies and promote consumer participation in decision-making. Other consumer groups have been established, such as the Health Issues Centre, an independent health policy and research centre and the Health Consumers' Council of Western Australia, an independent community-based organization.

Other channels of participation have been established by health departments in various states, including the District Health Councils in Victoria, and community representation on Area Health Boards in New South Wales. These initiatives have had a mixed record of success with problems including a lack of resources and difficulties in obtaining participants representative of the community.

The Consumer Focus Collaboration, established by the Department of Health and Aged Care in 1997, published a document, "*Evidence Supporting Consumer Participation in Health*" (2001) which summarizes how consumer participation has contributed to a range of outcomes related to the health system in Australia. An extract from this summary notes that:

- Active consumer participation in decision-making in individuals leads to improved health outcomes.
- Access to quality information facilitates decision-making and supports an active role for consumers in managing their own health.
- Active consumer participation leads to more accessible and effective health services.
- Effective consumer participation in quality improvement and service development activities in health services is achieved through the adoption of a range of methods.
- Effective consumer participation uses methods that facilitate participation by those traditionally marginalized by mainstream health services.
- Active involvement of consumers at all levels of development, implementation and evaluation of health strategies and programs is integral to their success.

The evidence identified in a number of these areas is discussed in the findings section of this report.

### 3.3.4 Organisation for Economic Co-operation and Development (OECD) Member Countries

The OECD published *Citizens as Partners –Information, Consultation and Public Participation in Policy-Making* (2001), a report based on the previous two year findings from extensive surveys, meetings and case studies of OECD member countries, coordinated by the PUMA Working Group on Strengthening Government-Citizen Connections. The report compares measures taken by the OECD countries to improve citizens'

access to information, expand opportunities for consultation, and promote active citizen participation in policy-making. The report notes that citizens are demanding greater transparency and accountability from their governments, and expect their views to be considered in decisions that affect them.

Governments in all OECD countries are under pressure to integrate public input into the policy-making process and the OECD surveys show that new forms of representation and public participation are emerging. Depending on the political or social context, the rationale for increased public participation may reflect different priorities, such as strengthening democracy (e.g. Norway), enhancing transparency and accountability (e.g. Korea, Italy) or achieving better service delivery (e.g. Australia, New Zealand, Spain, the United Kingdom). Canada has identified all three priorities in developing PI/CE strategies.

The survey results also indicate that government initiatives to seek greater citizen input into policy-making are relatively recent in most countries. All of the thirty member countries have significantly increased efforts to inform and communicate with citizens. However, active participation and engagement of citizens in decision-and policy-making is rare, and restricted to a small number of OECD member countries.

A number of OECD countries submitted case studies of active citizen engagement, including the following European studies:

- The Danish Government has made a practice of involving the public. Blume (2001) describes methods used in Demark to promote stronger citizen involvement in health care policy decisions including: surveys, user boards, mailings, public hearings and consensus conferences in which lay persons meet to hear experts and policy makers on a selected issue, deliberate amongst themselves and then provide a consensus view. All Danish counties are required to develop four year plans to set out health priorities and to involve the public in this planning process. One of the Danish counties, Aarhus, is used as an example where extensive consultation took place with mailings and public hearings. Blume indicates that little more that 0.1 per cent of the county's population actually provided feedback. However, the citizens involved were able to achieve some changes to the plan, e.g., the development of the county's first hospice, and more care for vulnerable families and those with alcoholism and psychiatric problems.

- Norway's experience with consensus conferences in 1996 and 2000 to address genetically modified foods is discussed by Morkrid (2002) and highlights both benefits and drawbacks. He indicates that the evaluation of the 1996 consensus conference did not assess the real impact on government decision-making on genetically modified food.

He observes that the different ministries working to prepare the final parliamentary proceedings with regard to genetically modified food tended to rely more on expert opinion that on the conclusions from the consensus conferences. However, Morkrid adds that it is important not to underestimate the potentially positive psychological impact on public opinion of involving citizen in decision-making on sensitive and complex policy issues.

These and other examples are further discussed in the OECD Citizens as Partners (2001) and in Stroick's paper (2002).

### 3.3.5 The United States

The United States has had a long tradition of public access to and participation in government. Public consultation nationally and in many states has involved environmental issues that have significant impact on health. Reeder (2001) points out that technology over the last number of years has increased the amount of information available to citizens and nongovernmental organizations about environmental issues and health risks. He contends that individuals and small groups will continue to need assistance to understand and interpret what is often complex information about the environment. He concludes that the need for traditional approaches to consultation has not diminished and may in fact increase as a result of greater electronic access to the policy process.

Another key area of concern in the United States has been a focus on the quality of health care and consultations on this issue have been numerous. One example is the formation of the National Roundtable on Health Care Quality (Institute of Medicine, 1998), made up of 20 participants from the private and public sectors, which met over a two-year period and used a number of different consultation methods to inform their deliberations.

A significant example across 14 states of engaging citizens and mobilizing communities to assume shared ownership for certain public health activities and create public health partnerships is know as "Turning Point: Collaborating for a New Century in Public Health" (2002; The Lewin Group Inc., 2002). Some lessons learned from this initiative are described in the findings section of this report.

# 4 Findings: Beliefs and Understanding of PI/CE and Quality Health Care Commonly Found in the Literature

There is an abundance of information in the literature that speaks to the importance of PI/CE in health care, outlining philosophical foundations of public involvement in health care; the perceived benefits of PI/CE in health care decision-making; and the characteristics associated with effective PI/CE that can impact the health care system. These understandings and beliefs are based on theoretical premises, general observation and expert opinion. Many authors nationally and internationally (see discussion below) appear to share certain common understandings about the public's involvement in health and therefore these are valuable in increasing our understanding of the potential contribution PI/CE can have on quality health care. A number of these understandings are outlined below.

## 4.1 Philosophical Foundations of PI/CE

There are two general approaches or schools of thought within the national and international literature that underlie the growth of interest in PI/CE, although there are variations on the theme (Church and Barker, 1998; OECD, 2001; Ridley and Jones, 2002). The consumerist approach views the consumer as sovereign in the marketplace. It emphasizes the importance of market research to identify the preferences of individual consumers. It also places emphasis on the rights of consumers to information, access and choice. This view underlies the efforts to give consumers an increased voice in health decision-making in relation to professionals and bureaucrats.

The democratic approach stems from the writings of liberal thinkers and sees people as citizens and taxpayers with the right to access services and to participate with others collectively in society. Equity and empowerment are important features in this school of thought. Public participation is seen as contributing to a healthy democracy. This view underlies the efforts to decentralize health care decision-making with more direct input from citizens.

## 4.2 Perceived Benefits of PI/CE

There is growing consensus that health care policy reform built upon citizen participation is desirable for many reasons. MacFarlane (1996) in her case study of the reform of Ontario's long-term care policy offers a number of observations on the benefits of PI/CE in health care:

- It promotes sharing of experiences and information.
- It generates better options.
- Citizens are more likely to implement solutions that they have been involved in identifying.

- Successful participation can result in the benefits associated with the self-help process such as learning effective ways to cope with problems, feeling less isolated, and gaining a sense of control over one's life.
- User involvement is seen as important when planning for reductions in health care spending.

MacFarlane argues, that aside from the benefits, citizens have a right to be involved in the health care system – "*it is their health and their money*."

Phillips and Orsini (2002) see multiple benefits from PI/CE and view the process as multi-faceted. The three main benefits that they summarize in their review of the literature include:

- Involving citizens in policy processes produces better policy.
- A number of different schools of thought agree that active civic participation fosters more responsible citizenship in that, through participation, citizens learn and practice the skills of citizenship, becoming more informed about issues, debating positions and making compromises.
- There has been a long standing perspective that citizen involvement contributes to building stronger communities. This stems from an earlier focus on community development to a more recent emphasis on building social capital.

Hyde (1999), for example, argues that "*the research on building the capacity of communities and the accumulation of social capital shows that how we organize our health systems – in both micro and macro contexts – is important, and that collaboration, flexibility, and community participation must become central in health structures.*"

Ableson and Eyes (2002) also point to the "new public participation" which is based on a perceived need for social capital to enable citizens in communities and organizations to solve problems collaboratively where trust is developed and a commitment to the common good is evident.

In looking at PI/CE in the health care system, Ableson and Eyes (2002) indicate that the benefit of PI/CE may never be a more efficient health system, and may, at times, contribute to the inefficient allocation of resources. However, they contend that the greater potential lies in its ability, through legitimate and accountable participation, to strengthen citizen commitment to health programs and policies, and to encourage the expression of democratic values.

Zakus and Lysack (1998) confirm that while the literature is seriously lacking in empirical studies that specifically demonstrate the impact of PI/CE, it is widely accepted, based on theoretical grounds and personal

experience, that PI/CE facilitates many positive outcomes. They cite the following benefits that have been identified in the literature:

- There is a heightened sense of responsibility and conscientiousness regarding health.
- Opportunity is created to educate citizens to the possibility of controlling their own destiny, resulting in a more equitable relationship between recipients of service and service providers.
- Greater dissemination of health knowledge results in the community.
- Additional training and experience acquired through participation in health may enhance future employment opportunities.
- Health services are provided at a lower cost – through greater opportunities for fundraising and access to volunteers.
- There is a better determination of the need for health facilities, their location, and personnel requirements.
- Resources are more often directed to the "felt needs" in the community.
- There is a decrease in feelings of alienation and less authoritative relationships between the community and health officials.

Pivik 's (2002) submission to the Commission on the Future of Health Care in Canada provides a compilation of the advantages to PI/CE in health planning reported in the literature:

- Health care decisions reflect the needs, values and culture of the community.
- Decision-making is more accountable to the community
- There is more efficient use of scarce resources.
- There is an enhancement of community awareness of health issues.
- There is increasing support for programs and services.
- There is increased networking between provider and community members.
- There is greater access to local resources.
- There is a mechanism for public feedback.
- There is an opportunity to train and educate community members.
- There is an enhanced sense of control and empowerment in the community.
- It provides the opportunity for different perspectives, pooling resources and creative problem solving.

Pivik (2002) also summarizes the challenges of PI/CE to include: resource limitations, poor communication, differing definitions of participation, conflicting vested interests, lack of representation, incongruence between stated purpose and practice, time restraints, difficulty reaching marginalized groups, and lack of knowledge and training in PI/CE. These challenges are apparent in an examination of regional health planning councils in Eastern Ontario (Weaver and Pivik, 1996) that specifically highlighted a need for adequate staff and time to pursue community

involvement, resources for training information, education and materials and financial resources for involving members.

Involving the public is viewed by many as a democratic and ethical requirement. Others view PI/CE as a way to legitimize decision already taken. Still others have associated with PI/CE with a range of general benefits to health care. Improved quality health care as a result of PI/CE often appears to be implicitly assumed, but is rarely explicitly stated as an outcome and measured.

### 4.3 Characteristics Associated with Effective PI/CE

There have been a number of attempts to identify the characteristics that are associated with effective PI/CE in general terms and in relationship to health care decision-making. A number of handbooks have been developed to provide a guide or road map for how to inform, consult and engage citizens in policy-making. (A few examples include: Citizen as Partners, OECD Handbook on Information, Consultation and Public Participation in Policy-Making, Paris France, 2001; Health Canada's Policy Toolkit for Public Involvement in Decision-Making, Health Canada, 2000; The Model Plan for Public Participation, National Environmental Justice Advisory Council, Washington, DC. 1996.)

Work in the environmental health area provides some important lessons for 'what works'. Caron Chess suggests that the key to successful PI/CE is 'getting the right participation' and 'getting the participation right'.

The 'right participation' means "*sufficiently broad participation to ensure that the important, decision-relevant information enters the process, that important perspectives are considered, and that the parties' legitimate concerns about inclusiveness and openness are met.*" While there is little research as to which approach to selecting participants is best in specific situations, a review of case studies suggests that a combination of approaches may be appropriate.

'Getting the participation right' means the process has been responsive to needs, information and viewpoints have been taking into account, and the participation has had an effect on desired outcomes. It is important to take into account the goals of the participation. Chess points out that for some, public participation may be a successful endpoint in and of itself. For others, success means that the participation led to an endpoint such as a consensus or plan, the implementation of a plan that was developed through PI/CE, or an improved health outcome.

A further factor to consider is the selection of the type of participation. While it is difficult to predict which type of participation will work in any

given situation, Chess indicates that this may not be the most critical factor. She indicates that the types of participation are tools and success may depend as much on how competently these are used as on whether they are the right tools for the job. Chess suggests that it is important to be able to modify the type of participation to suit the situation or change the participation over time. Others argue (Stroick, 2002) that you may need to use multiple forms of participation in a particular situation to enhance effectiveness. Other critical factors for a successful process identified by Chess include the timing of the participation, organizational factors and the overall context for participation.

# 5 Findings Re: Evaluation

This section identifies the challenges to evaluating the impact of PI/CE on quality health care. It presents some of the key evaluation frameworks and tools that are cited in the literature.

## 5.1 Challenges to Evaluation of PI/CE

The evaluation component of the PI/CE literature is limited with only a few studies undertaking any systematic evaluation using specific criteria or outcome measures. A literature review conducted by Abelson et al. (2003, in press) of empirical studies of deliberative methods in the health sector came up with only one systematic attempt (McIver, 1989) to evaluate a particular method of PI/CE using pre-defined evaluation criteria. Fewer et al. (2001) also refer to the paucity of information on the evaluation of different PI/CE exercises.

Zakus and Lysack (1998) emphasize that many of the benefits that have been identified for PI/CE and their contribution to health care quality are reputed benefits and empirical evidence to substantiate these benefits is difficult to obtain. They point to barriers in securing evidence on the impact of PI/CE that pose challenges for evaluation. For example, these include:

- The public involvement process is complex and the fact that it has different meanings and is not well understood creates problems of measurement.
- Disentangling the effects of participation from other effects is complicated.
- There are many difficulties in ensuring representation. All views, including minority view need to be respected. Methods used to select participants and the degree to which they represent local issues are critical in determining the perceived legitimacy of the representation. Who has a right to speak for the community is an issue. Who has the influence or authority to affect decisions is important, particularly when participant groups include both consumers and providers.

- The meaning of community is often blurred. Who are we talking about in terms of community participation?
- Dedicated resources are required to measure impact.

In looking at the impact of PI/CE on quality health care, the question could be asked – what aspects of efficiency does PI/CE have the potential to influence. Abelson and Eyles (2002) indicate that in economic terms there are three types of efficiencies: technical, cost-effective and allocative efficiency. They conclude that PI/CE is rarely seen as compatible with technical efficiency or the cost-effective functioning of the health system. They indicate that the notion of allocative efficiency has more relevance in that information obtained from the public about values, needs and preferences can contribute to the efficient allocation of resources within the health system.

Lasker and Weiss (2003) in their discussion of broad-based community participation and community collaborative practices and partnerships point to the sources of frustration relating to determining effectiveness. "*Thus far, it has been very difficult to document that broad participation and collaboration actually strengthen the ability of communities to improve the health and well-being of their residents.*" They cite the following reasons:

- Terms like community engagement, partnership and collaboration mean different things to different people.
- Efforts to engage people and organizations in community problem solving have been too short-term and insufficiently resourced to be fairly evaluated.
- Evaluations have generally looked at end results rather than investigating the impact of the collaborative process on the results.
- The multi-disciplinary nature of the collaborative process complicates the determination of impact by requiring diverse disciplines to work together and learn from each other.

A further challenge to assessing the impact of PI/CE on quality health care is the fact that quality of health care itself is complex, contextual, can have different meanings, and therefore, is not readily amenable to standardized measurement.

### 5.2 Evaluation Frameworks and Tools for PI/CE

The most comprehensive attempt to develop an evaluation framework for effective public participation is the work of Webler (1995) who identifies multiple indicators for the measurement of two key essential criteria - fairness and competence. Simces & Associates (2002) used this framework in evaluating the relative impacts of three types of deliberative dialogue methods, study circles, study groups and public dialogue on people's perceptions and understanding of quality health care in British

Columbia. They used these criteria, in addition to random assignment of participants, to minimize the unplanned variation between the dialogue groups which enabled them to compare the relative effectiveness of the different dialogue methods. They found that significantly more participants in study circles (four face-to-face meetings) than participants in study groups (four mixed sessions including face-to-face, telephone conference and internet) or public dialogue groups (single face-to-face session) 'strongly agree' that their overall understanding about quality health care increased as a result of participation.

Abelson et al. (2002) identify four key elements that could be used to design and evaluate PI/CE: representation, the structure of the process or procedure, the information used in the process, and the outcomes and decisions arising from the process. They discuss citizen juries in the light of these four elements and are able to identify the strengths and weaknesses of this PI/CE method. The empirical studies reviewed suggest that some methods may be preferable to others depending on the goals of the participation. They conclude that further study comparing various PI/CE methods needs to take place using an evaluation framework.

Frewer et al. (2001) present a framework and a toolkit for evaluating the success of public participation exercises. The framework and toolkit were tested using a range of different PI/CE exercises and using statistical and methodological approaches from within psychometric theory. The evaluation criteria they identify include: acceptance criteria such as: representativeness, independence, early involvement, influence, and transparency; and process criteria such as: resources accessibility, task definition, structured decision-making, and cost effectiveness. The toolkit itself contains three measurement instruments used to evaluate the participation process: a short participant questionnaire to compare the effectiveness of different exercises, a long participant questionnaire used to understand why a particular exercise successfully meets different criteria or why it fails to do so, and a checklist to ensure that the view of everyone involved in the process is taken into account.

The toolkit developed by Frewer et al. is designed to assess the participation process itself and the views of participants about the effectiveness of the process. It does not assess the impact of public consultation on health care decision-making or policy development. In fact most criteria discussed in the literature are procedural in that they look at what makes for an effective process. They are not substantive and do not measure outcomes, such as the quality of the decisions made or what impact the decision had. Further work on how to measure the outcomes of PI/CE processes is required.

Lasker and Weiss (2001) present a multi-disciplinary model that lays out the pathways by which broad participatory processes lead to more effective community problem-solving and to improvements in community health. This model of Community Health Governance (CHG) states that to strengthen the capacity to solve problems that affect health, communities need collaborative processes that achieve three key outcomes: individual empowerment, bridging social ties, and synergy. In addition, in order to achieve these outcomes, the process requires certain characteristics such as: the right mix of people, effective ways to involve people, feasibility, real influence and control, meaningful dialogue and group dynamics, and being sufficiently broad in scope to address the issues comprehensively. In addition, special kinds of leadership and management are required to achieve these characteristics. They conclude that this model can help researchers answer the fundamental effectiveness questions relating to community collaborations. The model clarifies meaningful community engagement and sets out a pathway to determine its impact on community health. This model further provides a comprehensive theory of change and a strong foundation for measurement that then enables comparative research.

Further work is required to refine evaluation frameworks and test their applicability. The danger of not introducing rigor into evaluation of PI/CE activities is that the public may not perceive the exercise as valid and relevant, and public confidence will be jeopardized.

# 6 Findings Re: Evidence Linking PI/CE to Quality Health Care

The purpose of this section is to examine the evidence that supports or refutes the hypothesis that PI/CE contributes to quality health care.

Overall, the empirical evidence that PI/CE contributes to quality health care is limited. As outlined in the previous section, demonstrating the impact has been limited due to the many methodological challenges. This is a field that has yet to undergo research rigor.

The evidence that does exist varies depending on the area of health care or health care decision-making being examined.

The link between PI/CE and quality health care is discussed below using the following categories:

- Values to guide health care
- Clinical care decisions
- Planning and development of health care

- Governance (including regionalization, resources allocation/priority setting, and quality improvement), and
- Community development/ collaborative practices

These categories have been chosen since they illustrate areas where considerable examples of PI/CE occur, they are categories commonly found in the literature, and decisions in these areas can impact quality health care.

Wherever possible, we identify from the literature the methodological approach to determining evidence, such as, critical review of the literature, case study, clinical trial or the use of surveys, focus groups, key informant interviews, or other research methods.

### 6.1 Contribution of PI/CE to the Identification of Values that Guide Health Care

Identification of values to guide health is an area in which decision-makers and policy makers consistently involve the public.

A number of reports in the literature illustrate that the public prefers to be involved in decisions about values that guide the health care system (Litva et al. 2002, and Lomas, 1977). Abelson and Eyles' (2002) review of public values in the health care system concludes that the public may be a *"critical ideal source"* of identification of values to guide the health care system.

There is some debate concerning the best method or methods of eliciting values important to the public. Abelson and Eyles' (2002) argue that the many surveys, polls and other methods used to date to elicit values do not reflect on how the public has reached these values. It is clear that there are many competing perspectives that determine values (e.g. democratic, pluralistic or individualistic values) and that the values of an individual may differ from the community or 'common good' values. It is therefore important to identify how the information about values is collected and interpreted, and how it is to be used.

Mullen (1999) in her work in the United Kingdom reviewed the various techniques used to elicit values, suggesting there are three important questions that need to be asked when determining which technique to use: appropriateness, aggregation and ease of use. While some researchers argue for the importance of techniques that are grounded in theory, Mullen proposes a more pragmatic approach indicating that different methods of eliciting values are equally good predictors of clients' preferences. What is important is the trans parency of the process, and the acceptability of the methods to the people participating. She

concludes that the measurements have to be tailored to the particular situation and the goals of the exercise, e.g., whether the goal is to elicit values at the community or individual level.

Regarding the link between identification of values and impact on quality health care, long-term impacts where the identification of values has led to changes in quality health care have not been reported.

Short-term impacts are noted where values identified by the public have been incorporated into key public reports, such as the National Health Forum (1997), the Quality of Life Indicators (Michalski, 2001) and the Romanow Commission (2002). Each of these initiatives used a number of methods to elicit values, including deliberative dialogue, and the resulting reports made recommendations that reflected the values identified. In addition, the process of eliciting the values was nation-wide, transparent and representative providing the legitimacy required for their acceptance as the values to guide the Canadian health system. However the long-term impact of these initiatives and the value statements on quality health care in Canada is yet to be determined.

### 6.2 Public (Patient) Involvement in Clinical Care Decisions

Within the United Kingdom, Australia, Canada, the United States and other OECD countries there is considerable discussion in the literature about the merits of involving individuals as users or patients in decisions about their own treatment and many examples are provided.

In this area there is some evidence that involving patients in decisions about their own health care leads to improved quality health care outcomes when specific criteria are met. The evidence to support this comes largely from randomized trials and case studies.

The conclusion drawn from these studies is that consumers/patients can positively influence their own health outcomes if they are involved actively in shared decision-making and provided with quality information and appropriate self-management tools. Where there is poor communication between care providers and patients, skills are not properly taught, or shared decision-making poorly defined, improved outcomes are not seen.

The studies cited in a literature review of consumer participation in Australia (Consumer Focus Collaboration, 2001) illustrate improved health outcomes for people with chronic diseases. For example, there was strong evidence that when adults with asthma are actively involved in their own care which involves self-management education and written action plans, they have reduced hospital admissions, emergency room visits, unscheduled visits to the doctor, days off work or school and nocturnal

asthma. These outcomes are substantiated in a clinical review article by Lahdensuo (1999). He based his work on his own experience as a clinical pulmonary specialist in charge of organizing asthma treatment, participation on several national and international working groups, and reviews and articles from high quality journals. He concludes that self-management of asthma prevents exacerbation, improves care and is cost-effective. Successful interventions combine provision of information and individualized self-treatment plans.

Similar results have been obtained by the Stanford University School of Medicine in the United States that conducted randomized trials of 952 patients with heart disease, lung disease, stroke, or arthritis undergoing a chronic disease management program. Other examples cited (Consumer Focus Collaboration, 2001) include studies of people with diabetes who achieve more effective control of their blood sugar level, people with hypertension who benefited from an active role in their own care, and women with breast cancer who were less likely to suffer depression and anxiety when involved in their own care.

A review of the literature published primarily in the United Kingdom between 1995-2002 (Ridley and Jones, 2002) also provides evidence from randomized trials of a positive impact of shared decision-making on physical functioning and patients' perception of their health.

Coulter and Elwyn (2002) argue that that while active participation in treatment decisions and in self-management of chronic conditions can benefit patients in the short-term and may lead to better health outcomes in the longer term, the evidence for this is still equivocal. They point to two significant challenges. The first is the need to ensure patient education is properly done so that the patient becomes an expert. The second is the need to develop self-management programs that are flexible and tailored to meet the unique needs of each individual.

### 6.3 Public Involvement in Planning and Development of Health Care

In local, national and international settings, the public (patient/patient groups) have contributed to the planning and development of health care services across a range of service areas and levels, but the impact of this involvement on the quality and effectiveness of health services is undetermined.

A systematic review of the literature (Crawford et al., 2002) was conducted recently to examine the effects of involving patients in the planning and development of health care. This is a worldwide review that includes published and grey literature between1996-2000. The authors conclude

that little information was found on the effects of the involvement. Out of 337 studies about involving patients in the planning and development of health care, 294 (87%) were excluded because they did not describe the effects of the involvement. The accepted studies included 42 papers (12%) that described the effects of 40 initiatives involving patients in planning and development activities. Of these, 31 were case reports, five were the results of surveys, three examined records or meetings and three described the findings of action research. Results showed that including patients led to the following:

- changes in the provision of services, e.g., making services more accessible, providing more information, or new services resulting because of the involvement,
- changes in attitudes of the organizations involving the patients, e.g., staff attitudes toward patients becoming more favourable, organizations being more open to involving patients, and organizations developing more initiatives to involve patients, and
- effects on users e.g., patients welcomed the opportunity to participate, self-esteem was increased. Some patients reported dissatisfaction with the process.

In a number of studies cited in this literature review patients were surveyed and asked to judge the effects of their involvement. A high percentage of respondents indicate that involving patients improved the quality of health services or led to improvements in people's health. However, the authors conclude that the "*evidence for the effects of involvement of patients on the use of services, quality of care, and or health of patients does not exist.*" Patients have contributed to the planning and development of services across a range of settings, but the effects of this process on the quality and effectiveness of services are unknown.

There are a number of case studies that are noted below that provide further insight into the link between public involvement and planning and development of health care and the impact of PI/CE in this area of health care decision-making.

The United Kingdom literature contains numerous descriptions of different mechanisms to involve patients and accounts of user and public experience and opinion. There have been few studies that have attempted to address the extent to which management decisions have been influenced or modified as a result of involvement (Milewa et al., 2002). For example, a review of community participation in the 1990's concludes from 75 interviews that political rhetoric is an issue and that a democratic deficit in health care planning exists (Milewa et al., 1999). The authors conclude, however, that there is a growing professionalism and active

management (rather than active citizenship) that is, in part, offsetting the democratic deficit.

The announcement in August, 2002 of a citizen's council to advise the United Kingdom National Institute of Clinical Excellence received press coverage indicating that patients see it as "a toothless tiger, a token gesture" (Gulland, 2002). Further, a number of recent studies in the United Kingdom have examined the primary groups and trusts established to determine the impact of public participation. Milewa et al. (2002) found the influence of health care professional and managers in these structures to be stronger than patients and citizens. However, they conclude that users and advocacy organizations are becoming increasing assertive and more involved in formulating local policy and local partnership structures.

Rowe and Shepherd (2002) studied 49 primary care groups within one health region in the United Kingdom to assess their response to directives to make patient and public involvement an integral part of the way they work. The work was conducted by means of a survey (self-completed questionnaire). The most often reported response to the purpose of public participation was to make services more responsive to user needs. Lay and clinical board members (as well as managers) accept that public involvement is a tool for gathering information on patient views to increase responsiveness of services rather than as a process of empowerment by involving users in decision-making. The results indicate that the public's role is limited to provision of information regarding health needs rather than an active and influential role in health planning, development, or quality improvement processes.

Other case studies of PI/CE in planning and development of health care illustrates more positive outcomes. For example, the Consumer Focus Collaboration reporting on evidence to support consumer participation in health (Australia, 2001) indicates that consumer and care provider participation in the design and delivery of mental health services helps ensure more responsive providers, better quality care and more empowered clients.

Kushner and Rachlis (1998) provide three case studies where health care policies have changed as a result of consumer involvement in planning and development activities. They cite:

- Consumers and long-term care in Ontario. A coalition of consumer organizations involving seniors conducted a variety of successful initiatives relating to long-term care reform including a policy proposal to create a network of non-profit neighbourhood multi service agencies.
- Consumers influence on breast cancer policy in Canada. Breast cancer survivors and their families were able to challenge the research and treatment community and direct attention to issues that were

important to them. Survivors have also been involved in influencing clinical guidelines for care and treatment.

- The Consumers' Health Forum of Australia. The consumer consultations contributed to policy development on a number of issues including breast implants, pharmaceutical education programs, and they had clear influence in the development of standards of GP practices as part of a process of accreditation.

The authors also point out limitations evident in each of the cases identified above that impeded consumer participation. These are similar to the challenges identified by Pivik (2002) in section 4.2.

### 6.4 Public Involvement in Health Care Governance

This section looks at the link of PI/CE and regionalization, resources allocation or priority setting, and quality improvement

#### 6.4.1 Accountability and Regionalization

Health reform, in many countries, in an attempt to increase accountability and citizen involvement has led to regionalization schemes that involve citizens in regional and local health boards or councils. There appears to be no objective measures to verify whether or not regional health authorities or lay participation within these authorities has improved the effectiveness, efficiency or other quality aspects of health care.

Dickinson (2002) in a paper submitted to the Romanow Commission about meaningful public involvement develops the position that *"Regional Health Authorities provide an effective institutional site for linking deliberative public consultation procedures to both the policy and operational levels (planning and implementation) of decision-making."*

However, a number of studies speak to the challenges that regional health bodies face in involving citizens. Professionals tend to dominate the decision-making process, and research and past experience provide little supportive evidence that health care quality has been improved. These conclusions are based on a review of studies that conducted literature searches, provided expert opinion, or presented results from surveys that researched participants' perceptions. Key examples are provided below.

Church and Barker (1998) conducted a literature search and as experts conclude that *" efforts to enhance citizen participation run into problems of professional dominance and citizen apathy."* Their review of the literature on regionalization in Canada, Norway, the United Kingdom, Sweden and the United States indicates that regional decision-making is dominated by

administrators and professionals. They confirm that there is a lack of evidence concerning the impact of regionalization on the efficiency and effectiveness of health care.

Lewis et al.'s (2002) analysis of health authorities in Saskatchewan used a survey method to assess the decision-making processes of boards. While they conclude that there are "*no objective measures to verify whether the regional health authorities have in fact developed locally sensitive mechanisms for improving effectiveness and efficiency,*" they found that respondents generally reported success. For example 63% believed that health care reform had increased control over health care services; 62% believed that the quality of health care decisions had improved; and 46% believed that the quality of health care services had improved. Lewis et al. also found that there were few differences in perception between elected and appointed board members. However, with elected boards, representation was skewed and there was low voter turn out.

Abelson and Eyles (2002) summarize Canada's 10 year experiment with regionalization and devolution and attempts to increase democratic control over health system governance, indicating that it provides an excellent laboratory for judging the public participation experience. They also conclude that there is little solid evidence to make any claims about whether and how increased democratic control has contributed to improved system performance.

Church et al. (2001) in their review of the literature conclude that "*past experience, as reflected in the literature suggests that there is no empirical evidence that the current mechanisms – boards of governance and advisory councils - adopted by governments to enhance citizen participation, accountability and responsiveness in health care decision-making are likely to be effective.*"

In a review of the literature, James Frankish et al. (2002) also point to the challenges associated with understanding the role or impact of PI/CE in regional health authorities. The authors identify difficulties in measuring the results of the work of the health authorities in terms of improving the quality of health care, and conclude that the effectiveness of lay health authorities has yet to be broadly tested.

### 6.4.2 Priority Setting and Resource Allocation

The literature addresses the involvement of the public in health care priority setting, how willing citizens are to engage in different types of priority setting priorities, and the appropriate methods that can be used to illicit preferences. There is limited literature that links the priority setting done by the public to subsequent change that effects quality health care.

Mullen (1999), for example, identifies six key areas for public involvement in health care priority setting: values, scope of health services, which group receives priority, location, non-medical decisions, and choice of individual treatment. She indicates that most of the controversial debates centre on rationing of services (what service for whom).

A number of studies focus attention on whether citizens prefer to make rationing decisions, and results in this area tend to be mixed or inconclusive. As noted below, some studies suggest the public is uncomfortable making resource allocation choices while others indicate citizens acquire the necessary self-confidence and skills for deciding how resources should be allocated, if given sufficient time and adequate support.

A literature review in the United Kingdom (Ridley and Jones, 2002) supports the finding that research evidence on involvement in rationing and setting priorities is contradictory. Some studies have found the public reticent of becoming involved in setting priorities, unless the priorities are at very general level. Research on citizen juries, for example, show that the public is willing to set priorities if given sufficient time and information.

These contradictory findings are repeated in other research work. For example, Lomas (1997) points to the public as being "reluctant rationers" of services, unwilling to take responsibility for setting priorities among broad health service categories or specific services. He indicates that the public do not feel comfortable making choices and they reject the task as requiring expertise they do not have. He indicates that identification of values is the only area in which the public sees themselves as appropriately involved.

In terms of what types of decisions might citizens be involved in, Abelson et al. (1995) used deliberative dialogue polling in Ontario with randomly selected citizens and attendees at town hall meetings and found that they prefer a consultative role. On the other hand, the majority of elected officials, appointees to district health councils and health experts were willing to accept responsibility for more specific types of decision. As decisions got more complex, support for traditional decision makers (provincial government and district health council appointees) was greater.

Singer (1995) indicates that Abelson's study may be limited by its methodology since it measured willingness to participate at one point in time. He cites other examples where citizens were willing to participate and make critical decisions. One example is the Better Beginning and Better Futures project funded by the Ontario government that involved parents and residents in developing programs, hiring staff and making

decision about location of neighbourhood centres and programs. Singer concludes from his analysis of the literature that given sufficient time, ordinary citizens can acquire the necessary self-confidence and skills to decide how resources should be allocated.

A more recent study by Litva et al. (2002) conducted within one health authority in the United Kingdom reports findings from focus groups and in depth interviews with informants randomly selected from members of the public, and from health and non-health related organizations. There was a strong desire in all groups for the public to be involved both at the program and system levels, without responsibility for decisions, but with the assurance that their contribution would be heard and that decisions taken following the consultation would be explained. The authors point out that this empirical finding does not appear to fit into the theoretical models of public involvement where consultation does not guarantee the views of public are taken into account. There was less willingness to be involved at the patient level. It was felt that the public should only participate at this level by setting criteria for deciding between potential beneficiaries of treatment.

A further study by Maloff et al. (2000) sets out nine outcomes of a public participation process and assesses these within the Calgary Regional Health Authority. They found that citizens are willing to made decisions about principles, values, client satisfaction, and input related to service delivery, but are less willing to make decisions about planning and setting priorities, distributing funds and managing services.

Martin, Abelson and Singer (2002) conducted a qualitative study consisting of interviews with decision-makers, including patients and members of the public. They conclude that members of the public can contribute directly to important aspects of priority setting and they provide insights into the different roles that the public can play and the contribution of each role.

The Oregon experience (Caulfield, 1993) illustrates a case where citizens played a large role in making resource allocation decisions that have implications for quality health care. A medical priority list was established by the Oregon Health Services Commission to be used to determine medical coverage. In order to ensure that the priority list reflected community values, town meetings, public hearings and telephone surveys of citizens were conducted to develop a community value component that was superimposed on the priority list. Some argue that the Oregon plan established a basic package of benefits and that by providing a greater amount of coverage to a greater number of people, it represented an improvement to health care. Others argue that the Oregon plan is unfair to the poor, particularly women, children and the disabled. They indicate

that the process was flawed for the reason that many of the public meetings were dominated by health professionals and the poor and disabled were underrepresented in the telephone survey.

Redden (1999) questions the degree to which "community values" in the Oregon Plan ultimately prevailed. The Bush administration rejected Oregon's application for Medicaid waivers on the basis that the process of community decision-making generated discriminatory results. There are important lessons to be learned from the Oregon experience about the difficulties of involving the public in rationing decisions. Although the Oregon plan has been widely recognized for its innovation in health resource rationing, Oberlander et al. (2001) find little evidence that explicit rationing has occurred or that the reduction in public coverage for services has produced substantial savings.

### 6.4.3 Quality Improvement

A review of the literature in the United Kingdom (Ridley and Jones, 2002) identifies innovative examples of how users have been involved both in defining and measuring quality, for example in the area of people with learning disabilities, quality assurance frameworks for hospitals, and people with mental health problems. While these studies do not examine the specific impact these involvements have had, they do contribute to our understanding of factors that should be taken into account when involving health care users in defining and measuring quality of services. For example, participation needs to occur on an ongoing basis for it to have a sustained influence on quality improvement activities.

The National Health Services Plan in the United Kingdom set up a number of bodies with citizen involvement responsible for monitoring the quality of services. Their impacts have not been evaluated.

Conference proceedings from the Consumer Focus Collaboration in Australia (2001) highlight the importance consumers place on being involved in the definition of quality improvement and call for an increased consumer voice in quality improvement. This implies support for consumers to engage effectively in defining performance indicators, developing report cards, improving quality from complaint systems and other forms of consumer feedback. In order for this input to have an impact, the report states, there needs to be a commitment to changing the way things are done based on consumer feedback and participation.

According to Levin (1995), public participation in assuring quality of medical care in the United States has become serious business, relentless in its discovery of inadequacies and its search for change. The People's Medical Society has uncovered unpleasant facts and has challenged

governments and professionals to remedy the situations. Overall, Levin argues that current strategies for quality control have not made significant improvement in quality of health care.

### 6.5 Public Involvement in Community Development/Collaborative Practices

Over the past 40-50 years there have been major initiatives aimed at involving communities in addressing health and social issues. This has been referred to as community development, collaborative practices, population health or community governance. The literature illustrates that these initiatives can have impact on improving quality health care and health outcomes, but that this does not occur consistently.

Ong (2000) argues that before one can effectively engage communities, it is critical to assess community capacity and social capital (features of social cooperation and for mutual benefit) to gain a realistic understanding of the willingness and capabilities for PI/CE in health care decision-making. Once you understand community capacity or the organizational capacity (Parker et al., 2003), then you can develop more appropriate methods and strategies for the PI/CE processes.

Analysis of PI/CE in community development initiatives, such as the Turning Point initiative, contributes to our understanding of the characteristics and conditions of PI/CE at the community level that can lead to improved health outcomes. The Turning Point initiative is a national broad-based collaborative strategy to improve public health infrastructure in the United States, sponsored by the W.K. Kellogg and Robert Wood Johnson foundations. Ongoing reports (NACCHO, 2001) and a multi-year evaluation (Lewin Group, 2002) of this strategy add significantly to our understanding of the complex relationship between PI/CE and potential impact on quality health care and health.

Turning Point aimed to establish a safe learning environment for partners to work collaboratively on analyzing and addressing the challenge of public health system improvement in order to protect and improve the public's health in the 21st century. In 1998 three-year funding support, technical assistance and national program office direction was provided to 41 communities across 21 states. Seventeen of these communities were subsequently awarded additional funds to continue innovative implementation activities.

Various efforts to evaluate the effectiveness of the Turning Point Initiative are reported on in the literature. In determining effectiveness, consideration is given to the achievement of a number of core strategies: innovations in collaboration for the public's health, increasing capacity for

policy development, and alternative structures for improving the public's health. The long-term goal is recognized as being improved health outcomes. In addition an intermediate indicator of success has been identified as increased social capital measured by recording and tracking the amount of participation in social events and activities in the community. Further, demonstrated changes to state systems relating to health are being recorded.

The Turning Point Initiative (2002) is highlighted in the Journal of Public Health Management and Practice (January 2002) describing lessons learned from the successful initiatives. Individual communities and states have reported wide variations in achievement of their health goals and in levels of enthusiasm for public health agendas. While each of the Turning Point projects is very different, six primary areas of activity that contributed to the successful initiatives were identified as follows:

- expanding the scope of public health practice to address social, economic and environmental determinants of health and quality of life issues;
- creating sustainable organizational structures beyond government to support collaborative decision-making and action;
- building local community capacity for assessing, monitoring, and reporting community health and well-being measures;
- adjusting policy environments and policy development processes to promote expanded collaborative public health practice and to support collaborative action;
- fostering broad public awareness and active engagement in the work of public health; and
- strengthening the human resources of broadly defined public health systems.

What has been learned from Turning Point and other community development initiatives is that collaborative practice is seen to better enable partnerships to address the wide range of medical and social factors that impact health and well-being. Collaborative approaches do not result in giving up control or access to resources, but increase capacity to protect and improve health. For example, the Lewin Group (2002) evaluated the overall Turning Point Initiative and illustrate with examples that partnerships that successfully mobilized the community made explicit commitments to broad civic involvement in decision-making and actual public health improvements.

Lasker et al. (2001) describe how to assist partnerships to reach their collaborative potential and identify how collaborations that involve people with different perspectives and engage communities improve community health. They indicate that the power of collaborations to improve health outcomes is dependent upon the ability to establish the following critical

connections: connecting individual-level services, broadening community involvement in population health strategies, and linking these two areas to enable them to work together.

For collaborative practices to achieve empowerment, bridging strategies and creating synergy that lead to improved health outcomes, certain characteristics are required: the right mix of people, effective ways to involve people, feasibility, real influence and control, meaningful dialogue and group dynamics, and being sufficiently broad in scope to address the issues comprehensively. These characteristics in turn are achieved through special kinds of leadership and management.

The case for community collaborative strategies for PI/CE is also presented in relation to rural health issues. Mackin (1997) indicates that community processes, such as rural health networks that open dialogue among business, government, the health care industry, and people who live and work in the community are critical to finding local solutions to quality health care issues.

The assessment of Turning Point, similar community collaborative initiatives in the health area, and other fields (case study in South Africa, Lyons 2001) are ongoing and the identification of best methods to measure the impact of community collaboration on improved outcomes is in progress.

### 6.6 Contribution of Different Types of PI/CE to Quality Health Care

Certain types of PI/CE have greater potential to contribute to quality health care than others. There are considerable benefits of a small mixed group of committed lay and health professional working together, especially when the objective is to increase the public understanding of particular issues. Examples of recent deliberative dialogue initiatives that illustrate their potential benefit as an effective method of PI/CE are outlined below.

In the Canadian context, an analysis of the citizen dialogue sessions undertaken as part of the work of the Romanow Commission on the Future of Health Care in Canada (2002), using a pre- and post-survey of participants, reveals more openness to change at the end of the eight hours of dialogue. Participants adjusted their "coming-in" stereotypes and came to recognize the merit and possibilities in approaches they did not originally like. The analysis indicates that citizen gain a greater sense of ownership of the health care system during the dialogue sessions. They go beyond their roles as users or consumers to see themselves as owners, investors, and stakeholder. Citizens felt that they had benefited personally from their participation in the dialogue. Citizens spoke of themselves as "*better judges of the system than those who deliver.*" They

want governments to listen to them and to respond. In addition the dialogue method fosters clarity about what citizens' truly value and the authors believe that this is critical for shaping reform. The authors conclude that citizen engagement helps to clarify how deeply held values are evolving with changing circumstances, that "*engagement only works when policymakers are ready to invest in learning and listening, when they are ready to open up discussion on the big conflicted choices and trade-offs, and when they place a high value on the process of public learning.*"

Another example that points to the effectiveness deliberative dialogue is the work by Zena Simces & Associates on engaging citizens in deliberative dialogue about quality health care in British Columbia (2002). One of the main purposes of this project was to identify how three different types of dialogue methods (study circles with several face-to-face meetings, study groups including telephone/internet, and public dialogue with one face-to-face meeting) affects people's perceptions and understanding of health care quality. Participants included a mix of health service providers, frequent and infrequent users of the health care system, recruited in four geographical locations in British Columbia, and randomly assigned by participant group to different types of dialogue sessions. To evaluate the relative impact of using different dialogue methods, an evaluation framework was established at the outset of the project to minimize variation and meet benchmarks of effectiveness. A pre- and post-dialogue survey was completed by participants with content analysis and observation methods conducted on the dialogue sessions themselves. Results illustrate the following:

- Participating in a dialogue process has measurable impact on participants' views and understanding of health care quality.
- More participants in the study circles (four face-to-face meetings) strongly agree that their overall understanding about quality health care increased as a result of participating.
- Common understandings and common ground can be reached among individuals with diverse perspectives and experiences.
- Social capital can be developed in that participants are willing to forego their personal agenda for the greater good of society. There is an increase in participants' understanding of what quality means to others.

Participants in this study, as in other work cited in this report, are clear that dialogue is important not for its own sake, but for its opportunity to influence change. Participants indicated they want to be heard and they want to know that their input will be considered.

Reviews of citizen juries (McIver,1998; Abelson, 2001) have found that citizen juries enable comprehensive consideration of particular health issues. Citizens tend to emerge from these types of initiatives with a fuller understanding of the complexities of the decision-making process. This is

achieved, with the assistance of a moderator, by ensuring that appropriate information on all relevant matters around the topic is provided to the jurors, with the opportunity to question and make a balanced assessment. Ground rules are established from the start. Participants welcome the opportunity to become more informed about health issues, but do express concern that the process takes a great deal of time.

Abelson and Eyes (2002) indicate that only "interested" citizens will be willing to devote their time to more intensive deliberative approaches and that people are most likely to become interested when an issue affects them. They suggest that participants are seeking "accountable consultation" and issue-based consultation is one way to meet the demand for more purposeful and meaningful consultation. However, they add, that the effects on decision-making are still unknown.

Frewer and Rowe (2001), using their evaluation framework (see section 4.2), compare a number of public involvement methods against two major criteria: acceptance criteria or those features that make a process acceptable to the public, and process criteria which are features of the process that are likely to make it effective. For example:

- Public hearings scored low on both acceptance and process criteria.
- Referenda, public opinion surveys and focus groups scored well on acceptance criteria but not on process criteria. These methods often do not have the resources to ensure the public is well informed.
- Negotiated rule making scored fairly high on process but not on acceptance since this has involved key stakeholders and not the general public.
- Consensus conferences, citizen juries or panels and citizen advisory committees scored fairly high on both acceptance and process criteria.

Fewer and Rowe (2001) however, indicate that it is difficult to conclude that any one method of public involvement is the best at the present time. In their opinion a combination of approaches providing alternatives to more standard processes will prove to be most suitable for engaging the public.

Stroick (2002) contends that Canada has engaged in a number of recent examples of PI/CE where a combination of approaches has been used and can be considered a leader in 'innovation by combination.' One of the best examples she presents where multiple methods were used to involve the general public on a variety of health issues is that of the Canadian Blood Services. The methods used include: public involvement in governance (2 members of the board are appointed to represent consumer views), education and feedback on the web, information and feedback via toll-free telephone, survey and focus groups, a public advisory panel that consults with blood donors about twice a year on

specific issues, expert advisory committees, consensus conferences, provincial stakeholder reference groups, and national liaison committees. Unfortunately, there has been no formal evaluation of the impact of these multiple approaches on decision-making, a renewed public trust, or the quality of services provided.

# 7 Summary of Key Findings

The following provides a summary of the key findings resulting from the review and analysis of the literature designed to better understand the link between public involvement/citizen engagement and quality health care:

- Many examples of PI/CE in health care decision-making are found in the national and international literature. The literature illustrates that many countries value PI/CE and have implemented different types of PI/CE in various aspects of the health care system.

- There is a great deal of variation and imprecision in the terms used to report about PI/CE.

- A number of typologies and frameworks classifying PI/CE in relation to health care decision-making have been developed, but have not been widely tested.

- A number of evaluation frameworks to assist in measuring the effectiveness of PI/CE in relation to health care or health outcomes have been developed, but their application has been limited.

- There are many examples in the literatures of reputed benefits of PI/CE in relation to health care or health outcomes.

- Overall, there is limited empirical evidence to support or refute the hypothesis that PI/CE contributes to quality health care. The evidence varies depending on the area or level of health care decision-making.

- The literature points to the public being a critical source of value identification for quality health care and outlines best methods for eliciting or aggregating these values. Shorter-term outcomes, where values identified by the public have been incorporated into key reports and documents, are prevalent. Whether the public's involvement in identification of values has a longer-term impact on quality health care is yet to be determined.

- There is evidence that involving patients in decision about their own care leads to improved quality health care or improved health outcomes when specific criteria are met.

- The public (patient/patient groups) have contributed to the planning and development of health care services across a range of service areas and levels and in many different countries, but the impact of this involvement on the quality and effectiveness of health services is undetermined.

- Health reform, in many countries, in an attempt to increase accountability and citizen involvement has led to regionalization schemes that involve citizens in regional and local health boards or councils. There appears to be no objective measures to verify whether or not regional health authorities or lay participation within these authorities has improved the effectiveness or efficiency or other quality aspects of health care.

- There is little research looking systematically at the publics' involvement in or preferences for being involved in particular types of rationing decisions or priority setting. Results from available studies are mixed or inconclusive. Some studies suggest the public is uncomfortable making resource allocation choices while others indicate citizens acquire the necessary self-confidence and skills for deciding how resources should be allocated, if given sufficient time and adequate support.

- Over the past 40-50 years there have been major initiatives aimed at involving communities in addressing health and social issues. The literature illustrates that these collaborative community-based initiatives can have an impact on improving quality health care and health outcomes, but that this does not occur consistently. Analysis of these initiatives has contributed to the understanding of the key characteristics and conditions that lead to effective involvement at the community level.

- Certain types of PI/CE have greater potential to contribute to quality health care than others such as deliberative dialogue methods and community collaborative practices. Using a combination of approaches lends itself to more effective PI/CE.

# 8 Discussion of Key Findings

What can be learned from a review of the link between PI/CE and quality health care at this point in time?

First and foremost it is critical to clearly define what is meant by PI/CE, what meaning of quality health care is to be used, and what the goals of public participation are in terms of health care. While a number of frameworks and typologies have been developed to clarify and classify the different types of PI/CE, there is a need to review these frameworks in the light of more recent experience with deliberative dialogue methods to ensure the frameworks are meaningful and relevant to the current context. In addition, further work is required to determine the usefulness of the framework in evaluating the impact of specific types of PI/CE on specific quality health care strategies or types of health care decision-making.

As discovered, outcome studies that examine the impact of PI/CE on quality health care are rare. However, the fact that there is limited measurement and empirical evidence of impact does not mean a link between public involvement and quality health care or health outcomes does not exist. The lack of outcome studies reflects both methodological issues and challenges.

Recognizing some of the challenges of measuring outcomes, more attention needs to be paid to the:

- distinction between process outcomes and results-oriented healthcare or health outcomes;
- identification of various methods for evaluating impact that include pre- and post-evaluation, longitudinal studies, comparative analysis, and more careful theorisation and theory testing.

In addition, evaluating the outcomes of PI/CE requires a much longer-term view than evaluating the process of PI/CE. Some outcomes may follow more quickly after PI/CE initiatives and some may take much longer to become evident. Time frames for evaluation and methods for collecting data will need to take into account short, medium and long-term outcomes and identify appropriate indicators for each.

As Abelson and Eyles (2002) point out, if public involvement in the health system is considered a value in its own right, then how success or failure is judged and what level and type of evidence is used may need to be carefully considered. Participation may never produce efficiencies in the health care system, but citizen involvement may help to strengthen citizen commitment to health programs and encourage expression of democratic values.

From an analysis of the overall literature, it seems apparent that citizens want to be involved in a meaningful way and want this involvement to make a difference. Participants in PI/CE are clear that dialogue is important not for its own sake but for its opportunity to influence change.

There are strong indications that regardless of the type of PI/CE involvement, certain features or characteristics need to be inherent in the process for measurable impact on quality health care to occur.

Involving patients in decisions about their own health care leads to improved quality health outcomes if the patients are involved actively in shared decision-making, provided with up-to-date information about their treatment options, and given effective education on self management tools. These self-management programs must be flexible and designed to meet the unique needs of the individual.

Evidence of the long-term impact of values on quality health care is yet to be determined. Tracking mechanisms and longitudinal studies are required to determine how the values statements have guided or been interpreted in the health care system and what changes occurred as a result. Nevertheless, there are important criteria for ensuring public values are elicited competently, such as, clear identification of the goals, transparency of the process, appropriate representation and acceptability of the methods to the participants.

In the area of PI/CE in health care planning and development there are examples where health care policy has been changed as a result of these public involvement activities. Case studies (Kushner and Rachlis, 1998) teach us that public involvement will not have an impact on planning and development of health care unless:

- The PI/CE is adequately funded.
- Groups have democratic processes for selecting representatives and those who sit on policy-making bodies are accountable to the people they represent.
- Survivors of illnesses are involved in the process.
- Participants are provided with adequate information to enable them to address their needs.

In addition, creating linkages and forming alliances among groups can create united positions on specific health reform and change the balance of the debate having greater influence on the outcomes.

In examining governance, in particular regionalization processes that have involved citizens in regional and local health boards or councils, there appears to be no objective evidence to verify whether regional health authorities or lay participation within these authorities have improved quality health care or health outcomes. This raises a number of issues,

such as, difficulties in applying objective impact measures and the challenges to clearly defining what effective governance for health care means. In addition, more research is required to examine how regional health authorities can use different methods of PI/CE effectively to facilitate results-oriented governance in health care.

Much can be learned from the recent research and methodological developments in PI/CE in community development, also referred to as collaborative practice or community governance.

In community development, there are also certain features or characteristics inherent in the initiatives that demonstrate measurable impact on quality health care or outcomes. These include: the right mix of people, effective ways to involve people, feasibility, real influence and control, meaningful dialogue and group dynamics, an initiative sufficiently broad in scope to address situations comprehensively, and the appropriate leadership and management to achieve these characteristics.

Therefore, we conclude that regardless of the type of PI/CE, for measurable impact on quality health care to occur, it is essential to pay attention to" getting the right participation" and "getting participation right". Effective PI/CE is a matter of achieving the best fit.

Core values for the practice of public participation have been developed and can serve as a guide to ensuring effective PI/CE.[1] These include:

- Democratic values – people should have a say in decision about actions that affect their lives.
- Making a difference – The public participation should influence the decisions.
- Inclusiveness – The public participation process communicates the interests and meets the needs of all participants.
- Outreach – The public participation process seeks out and facilitates the involvement of those potentially affected.
- Form of Participation – The public participation process involves participants in defining how they participate.
- Feedback – The public participation process communicates to participants how their input affected the ultimate decisions and outcomes.
- Informed Participation – The public participation process provides participants with the information they need to participate in a meaningful way.

Further work is needed to consolidate a framework that represents the key features of PI/CE that are necessary to achieve and measure improvements in quality health care and health outcomes.

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[1] Adapted from: Interact: The Journal of Public Participation, Vol 2, No. 2 Spring 1996.

In synthesizing the learnings from the literature the authors of this report propose the following initial elements of a model of PI/CE that is most likely to result in improved quality of health care:

- **Readiness**. There is commitment to effective PI/CE by all decision-makers, feasibility and opportunity costs are assessed, community capacity is understood, real influence and control of participants over the process and decisions are planned, timeliness and early involvement of all participants are considered, long-term commitment is outlined, and accountability for results is established.

- **Common Goal**. There is clarity of goals (addressing particular issues or problems or joint concern), clearly defined results to be achieved for the immediate and long-term, transparency of intent, and sufficient scope for comprehensive problem-solving or meaningful results.

- **The Right Participants**. Individuals are willing to participate, and the opportunity to participate is inclusive, representative, broad, diverse, and engages those who are affected by decisions.

- **The Right Process**. The process is fair and competent, a right fit with goals, utilizes methods of involvement that are most likely to have an impact on quality health care, enables meaningful dialogue (deliberative dialogue methods) and collaborative practices, and facilitates productive group dynamics.

- **Appropriate Supports**. Supports include: information and knowledge sharing, ongoing access to needed and usable information, training and education opportunities, appropriate tools, sufficient time, sufficient financial and staff resources, and elements needed to build community capacity for effective involvement.

- **The Right Leadership**. There is leadership to guide the processes toward desired results, facilitate working together, ensure required features for effective PI/CE are implemented, adapt to changing needs, and coordinate follow-up.

- **Evaluation.** Both process and impact evaluation is incorporated from the start of the initiative. There is an evaluation framework based on evidence or theory, clear identification of definitions and methodologies used, and clarity of goals to be achieved.

# 9 Future Directions and Considerations

What can Canada learn from the national and international literature examining the link between PI/CE and quality health care?

Governments wishing to implement PI/CE initiatives that will lead to quality health care need to take into consideration what has been learned to date regarding the key features of *effective* PI/CE. However, further efforts are also required to enhance our knowledge, understanding and success in this area.

Health Canada could assume a leadership role in linking PI/CE to quality health care by supporting or undertaking a number of strategic actions, including but not limited to:

- Further development and testing of a model of effective PI/CE to improve quality health care and improve health outcomes.
- Refinement of a framework to evaluate the effectiveness of PI/CE that considers process and result outcomes.
- Development of evaluation tools that address the methodological challenges in establishing empirical evidence regarding the impact of PI/CE on quality health care.
- Support further research and evaluation of promising PI/CE methods, such as deliberative dialogue, that foster common understandings and shared learning and can contribute to improved collective decision-making.
- Work with provinces, territories and regional authorities to identify opportunities to pilot and test collaborative practices as an effective PI/CE method to improve health. Engaging in collaborative practices at the community level could enable regional authorities to increase understanding of how different governance structures can facilitate improved quality health care.
- Support evaluation of the intermediate and long-term impact of current PI/CE initiatives such as the Romanow Commission to determine if the values identified by citizens are carried through to the implementation process and can be linked to improvements in health quality. This becomes an issue of accountability and may require ongoing involvement of citizens at different stages of the process over time, or new processes of accountability.

- Work with new initiatives that could benefit from PI/CE, such as the proposed national Health Council and the primary care renewal strategies, to facilitate the implementation of key features of effective PI/CE that would contribute to improved health care outcomes.

- Support initiatives that further education and training toward effective PI/CE.

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